

***Seizing Life* ®, episode 112**
From Desperation to Hope: The Founding and Future of CURE Epilepsy
Guests: Susan Axelrod and Barbara Kelly
(Transcript)

Kelly Cervantes: Hi. I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy. Today, on Seizing Life I am so excited to welcome two incredible, longtime advocates for epilepsy research, Susan Axelrod and Barbara Kelly. They were vital to the formative years of Cure Citizens United for Research in Epilepsy, the organization now known as CURE Epilepsy. Their passion, determination, and refusal to accept the status quo of epilepsy care for their children led to the emergence of CURE as a boundary pushing innovative leader within the epilepsy community. 25 years later, their vision and hard work continue to inform the research that CURE Epilepsy funds today and positively impacts the epilepsy community at large.

Susan and Barb are here today to discuss the early days of CURE, its impact on epilepsy research and their hopes for the future of the organization and advances in epilepsy. Susan, Barb, thank you so much for joining us today. I have to say I have been looking forward to this conversation ever since it was put on my schedule. I didn't come in to CURE Epilepsy until close to the 20th year, so much of the origin stories and your personal stories it's like CURE Epilepsy folklore, and so I'm just so excited to hear it from your mouths and to hear that history, and to get a better understanding of your vision for CURE's future. So to begin, I would love to know how you two first met.

Susan Axelrod: Barbara and I met at an epilepsy parent support group outside Chicago some years ago, and it was the first of its kind in the area, and we bonded with each other fairly quickly as I recall because we really had not yet met other parents of kids with epilepsy. As Barb can attest, it's always been a very lonely diagnosis, and prior to the internet, which it was very hard to meet people. And going back 25 years is sometimes not the easiest thing, so I will defer to Barb on whether that is an accurate memory.

Barbara Kelly: I distinctly remember that parents support group and thinking, "Is this all of the information and help we can get? We've got to do something different."

Kelly Cervantes: Yeah. Before going much further, I do want to get your personal history about what brought you to that support group that day.

Susan Axelrod: My daughter, Lauren, was born in 1981, and in 1982 when she was seven months old, her seizures started and her seizures started with a vengeance. It was one seizure after another. She was hospitalized quite frequently on endless numbers of medications in various cocktails and as I mentioned, I felt very alone. I thought she probably was the only child with epilepsy whose seizures could not be controlled because, for goodness sakes, this has been known since biblical times. And I actually think that I saw a notice of this support group in a doctor's office, but Lauren was probably well into her teens at that point, so I had spent a lot of years just being alone, and it was an amazing experience to meet other people like Barbara, and learned that I wasn't alone.

Kelly Cervantes: So this support group is in the mid '90s that you're attending. Barb, what brought you to the meeting that day? It was your son who's diagnosed, yes?

Barbara Kelly: Yes, my son.

Kelly Cervantes: And can you tell us a little bit what you're comfortable sharing about his journey, briefly?

Barbara Kelly: Marty had a seizure at two years of age. He was seen at one of the major centers, and he was put on Phenobarbital at that time for two year, and after that time they felt that he no longer needed it and progressed. And then later when he was 16, he had a massive seizure and was hospitalized at Mass General in the east where he was in school. He lives a very full life now, but there's so many restrictions and years of drugs, and years of never knowing when the next one would strike. It completely compromised his future, and of all my children, I would be the most proud of what he has accomplished because he's had the toughest uphill climb. And so he's work is full-time and he's independent in many ways, but in other ways with all the darts in that you can see that his future is on a different trajectory than the others in his family.

Kelly Cervantes: Now, you've both established that there was this loneliness, there was this lack of information, and certainly lack of access to the information that existed, and I know that that was part of what brought the two of you together. However, there's a big jump from recognizing a problem and going on to start a research foundation. So what was it, I know it was in 1998, CURE was founded by a group of mothers. What was the impetus that took you from that leap from recognizing the issue and then going and doing something about it?

Susan Axelrod: I think for me, one of the things that it took me a while to wake up to is the fact that we were all talking about how to live a life as well as possible. The motto in the community was living well with epilepsy, and as we were watching our children, our loved ones deteriorate, not be able to live anywhere near the lives that we had envisioned for them or hoped for them, and watching people pass away. It took us a few years I would say, to realize that we were each on the same wavelength but hadn't maybe articulated it yet, that this was not the goal we wanted to be working together on.

And at that point some of us began to look and think about why are our children suffering? So some certainly are very responsive to medications and can go on to lead good, happy, healthy lives, but our loved ones went, and why was that in this day and age? And so that's when the conversation around the table, literally around the kitchen table started to go toward, "What is the NIH doing? Why is this such a hard beast to tackle?" Barb, I know our kitchen table was a meeting place for a lot of us who, over not too long a time, but it took us a little while I think, to change our thinking from we were not any longer willing to accept this living well, accept the status quo. We wanted and needed to change it.

- Kelly Cervantes: So Barb, is it safe to say that the CURE's mission and vision has always been to find a cure or cures as the case may be?
- Barbara Kelly: Well, as Susan said, we felt like the statement living well with epilepsy was a contradiction in terms. And we thought too many people have sat back and decided, "Well, we're doing the best we can," and we're thinking if this is the best we need to stir some waters or attack the problem, really we were on a crusade, I think, with the lack of new treatments or access to the treatments, more information and with all the progress with all the diseases.
- And you look at epilepsy and at that point it was in the dark ages. It wasn't in the 1800s, it was in the dark ages still. And we also wanted to know we were doing the most we could for our child, but we thought we knew realistically that many of the complications had already taken place for our children. And we did not want to sit by and watch another generation of children grow up experience what... And the other mothers in the group were all of the same consensus. We needed to do everything we could. We did have fathers with us and without the fathers we wouldn't have been any place either too, so it became really a crusade for us.
- Susan Axelrod: And I think we realized over time all of our kids had different types of epilepsies. This is, as we all know, an incredibly complicated disease. And some like my daughter had failed over 20 different drugs in various combinations. She was evaluated for surgery, but it was ruled out as an option. The ketogenic diet, vagal nerve stimulation, and you start to go, "What are we doing?" Because you'd go to the doctor's office and it was simply a matter of, "What have we not tried yet?" There was no real sort of look at what was causing it. And what was causing Lauren's seizures versus what was causing Marty's, and we really wanted to know, "Why did I put a seemingly healthy seven month old baby into her crib one night and wake up the next morning, and think that she had died during the night because she'd had so many seizures? What is happening in that brain and why can't we address it more rationally rather than just throwing one drug after another at it?"
- Brandon: Hi. This is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over \$90 million to fund more than 280 epilepsy research grants in 17 countries. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.
- Kelly Cervantes: I think it's so important to remember that as you're talking about this, this is 1998, literally 25 years ago, but it's just not that long ago, so I want to keep that peace in everyone's mind as we continue to move forward with the conversation. So today we are known as CURE Epilepsy, but that was not always the name of the organization. Originally, we were Citizens United for Research in Epilepsy shortened to the acronym CURE. How did you come up with that name? What was the inspiration behind it?

Susan Axelrod: Well, the inspiration was as the name would indicate, a cure for epilepsy, not just yet another therapy that might work for some of the patients some of the times and just reduce seizures, but really getting to the bottom line about why a certain brain becomes epileptic and what can we do about that, and let's understand that better and address that rather than just addressing the symptoms. And I do remember CURE being the driving force behind what our goal was. I can remember, I don't know where we were, but I was in the car with my husband and I have a sheet of paper, I'm writing down, "What can this stand for?" Because we felt like it needed to stand for something, and that was how we came up with Citizens United. But CURE was the first, CURE was it. And then we added, we figured out what the C, and the U, and the R, and the E could stand for.

Barbara Kelly: We were so driven with determination, we wanted a big, bold statement that was very clear that we needed to take a new look at epilepsy as something that could be cured at some point, but certainly something that needed more attention in a really more of, it was a battleground as far as we were concerned and it needed to be attacked that way.

Susan Axelrod: And I will add that there was not I, and I think to date it may be our biggest impact on the field is that, there was not conversation about curing the disease. And in March of 2000, there was a White House initiated NIH conference that it just turned the tables on how we were looking at the disease. And I think there were people who came into this two and a half day meeting thinking cure epilepsy. And they came out of it and these were the researchers saying, "We never thought about it," but they were invigorated, excited, really embraced the whole concept.

And it was, I think, remarkable to me that people hadn't thought about it, and that was the acceptance that we found ourselves, the acceptance of the status quo, "You have epilepsy." One of our co-founders, Michael Smith, I remember well him saying... He's an epilepsy specialist at Rush in Chicago, and he said it would be going in to see your cardiologist and having them say, "You have blocked arteries so you can go home and expect to have so many heart attacks a year." I mean, why did patients accept it? Why did treating physicians accept it? And because they did, the research lagged because nobody was making that rallying cry.

Kelly Cervantes: Now, at the time that you started CURE, like you mentioned, the internet wasn't really a widespread thing. I had the fortune double-edged sword, I think, of having the internet where I could. I'm up at 3 o'clock in the morning, and I can't sleep and I'm reading a white paper that I found on Google on one half of my screen, and I have a medical dictionary on the other so that I can decipher what all of this means. But you didn't even have that with a layperson's knowledge yet here you are, two moms who know all there is to know about their children, but still that information isn't accessible. How does this group of mothers, of parents go out and find out what research needs to be done? How do you access the researchers enough to speak knowledgeably about this?

- Barbara Kelly: When I look back, and I talked to different ones periodically, still, different researchers, and what they say is that we were so passionate and we were so determined to do everything we could to help them find the answers, to promote more research, to raise funds for research, and we listened to them. And I can't tell you how many have said that, "You listened and you acted on what we were telling you," and they were so generous in directing us who to ask, who to talk to, but we also listened and heard what they needed. They needed people, they needed more funding and we could provide some funds, but our initial grants were small in the scope of funding research and labs, but we did take chances. Mothers and parents are more desperate, and I think it was our willingness to look at some new directions and step back from the problem and think, "What can we as lay people contribute?"
- Kelly Cervantes: Well, and I have heard specific stories about you, Barb, at the American Epilepsy Society Conference, literally chasing scientists, researchers down the hallways, trying to get them to help and to get them excited about CURE, and I personally love the visual of that. Was Cure the only lay organization attending these scientific conferences at the time? Were parents attending these or was it just you guys?
- Barbara Kelly: There were some others, but not in force, I don't think. And we were passionate and we were determined, and I don't think I literally chased them. I spent every waking hour there as did Susan working in a group, going to sessions, trying to learn. I mean, I think they tolerated us initially because we were appropriate and we were desperate to learn, and we attended everything we were supposed to. But then as it evolved, and the incredible generosity in willingness to help us of the group was unbelievable. And because we appreciated everything they did, we also, being the mothers thought, "Well, we have to do some little payback," and we did. Initially, we had a reception for the researchers who we were awarding grants to, and we tried to make it very special, although we were very careful with our money. Susan and I bought a little paper and everything else and did that kind of thing.
- But we knew that maybe we needed to spend some money trying to say thank you and that, I think, also served us well because Susan attracted so many of the stars in epilepsy research to our events that they came and it was a ticket in. And I can't tell you how many say, "Oh, going to your reception was just unbelievable," so I think it was a two-way street, and the grants we gave at that time were very significant to us, but in the scope of doing epilepsy research, when you think of the postdocs and all the expenses of doing, it was incredible. We got them to work on our projects for the money we had at that time.
- Kelly Cervantes: That's the way to get anyone to a party, I guess, college kids, researchers, you just give them some cocktail and hors d'oeuvres, and they come streaming in. I'm curious, you're talking about the researchers, and I want to know how, you started that grant review process. Who was responsible for reviewing the grants in those early days?

Barbara Kelly: Once again, we have to say thank you to the Epilepsy Research Committee in their generosity in doing it, and then being among the scientific advisors. They would take the time to walk through the review and structure it. I mean, I was a Philosophy major, how [inaudible 00:22:25] set up the research stuff? I don't know except through the dedication of those researchers, both the clinicians in the research, to helping us and guiding us and steering us in the right direction.

One of our other gifts was the fact that because we were desperate to see some different research that might affect different children and different people, that we were willing to take chances and we could see that so many of the really bright and very creative researchers needed to have a lab and they needed to have students there. And one of my dreams has always been to have a mentor award for the senior scientist who encourage these young people and keep them in the field, and it was also one of our goals to attract and keep people in the field of epilepsy research, so I think it's a two-way street always.

Kelly Cervantes: Well, and correct me if I'm wrong, Susan, but it's also my understanding CURE is patient driven research, patient focused research. So in addition to our scientific researchers, there has always been lay research reviewers as well, is that correct?

Susan Axelrod: Yeah. That's correct. That's always been one of our core values is to have a focus on patient-driven research, patient-focused research. We have sat in the rooms, and to build on what Barbara was saying, I think that as much as we got out of our sessions sitting around reviewing grants with our research committee, I think they also in the same way, the two-way street, got a lot out of, first of all, just understanding more. We would say, "Well, that's not important. That particular focus of that grant is not important to us, this is." And so they would learn what was important to patients and the motivation, and the hopes of patients and loved ones. And so that was just great synergy. It really, I think, worked well for us. And I think as much as we got out of it in terms of our learning curve for the science, they also felt supported.

I mean, and without naming names, I know of somebody who used to come and sit on our advisory board, and I've heard subsequently from his wife who has gotten involved with CURE that the reason she did was because she saw the change in her husband after he... And he'd been in the field a while, but there was something just energizing about his time spent with us at CURE and for him, recognizing how important the work is and how much it means to lives, and how overlooked it has been.

And one of the things that I think Barbara has brought to CURE in her time with us was not just helping us to get a group of researchers and scientists together that knew the field, but also she was so tuned in, keyed in on the personalities and where they came from and how they would interact because you could put six of the greatest minds together and get nowhere. But Barbara had this ability to know who was comfortable in a room together, where that interaction that would be fruitful would come from, and so we were very fortunate to have her,

not just her scientific skills that she learned, but also her understanding of human nature and community.

Kelly Cervantes: I love that. Going back even further a little bit, how did you start fundraising? Where did those initial donors even come from? Because fundraising is a challenge, and you're talking about fundraising for research grants, that's not small money. I mean, you're talking about tens of thousands of dollars per grant. What tactics did you have at the beginning?

Susan Axelrod: I would say we got incredibly fortunate with the timing at the beginning of CURE because our very first fundraising event was keynoted by then, First Lady, Hillary Clinton. She came to Chicago, she visited some patients in the hospital. She looked at EEGs, she learned a lot herself. And then she came and did the keynote address at our very first fundraiser in January of 99. So three months after we became a 501(c)(3), we got a word that she could do it with six weeks notice over the holidays. We put together this event that was fabulous and just one of those things being in the right place at the right time with somebody who can bring people into the room who were not connected to epilepsy but, perhaps, knew us, knew our story, learned some stories there and she brought them in. And so it really just put us on the map, and I think that was another jaw dropping experience. We raised more money than we ever anticipated at our first fundraising event, and that got the ball rolling for us very nicely.

So sadly, in this world of disease advocacy, you've got to raise awareness about your disease, and if you can get a public figure to come and be an advocate for you, it always helps. And I've heard that from the directors at the NIH who have said, "We need patient advocates. We need people out there making noise about the need for this research and this disease." It also was the time after that event where we had so many comments, notes, letters afterwards from people saying, "I had no idea. I had no idea what epilepsy was all about," and that was when we revisited our mission statement and said, "Honestly, I could care less if anybody knows about epilepsy because I want to end it." So our mission is not to raise awareness except as a vehicle toward raising more dollars for research, and that was a moment where we revisited and added the awareness component, realizing that we had to elevate the profile of epilepsy or we were not going to get anywhere.

Kelly Cervantes: And I think it's still something that we struggle with today, that awareness, and I think there's a multitude of reasons for that. As much as we want to put all of the money toward research and finding a cure, you can't raise the money if people don't know why you need the money, right?

Susan Axelrod: Yeah. Nonprofits have a special challenge in that you're not supposed to spend your money on anything other than the mission, but if you don't, you're going to be spinning your wheels forever.

- Kelly Cervantes: I want to take one last opportunity of looking back on the last 25 years of this organization and find out from each of you, what accomplishment that CURE Epilepsy has achieved that you are the most proud of?
- Susan Axelrod: I would say that our initial emphasis on a cure rather than simply treating symptoms was a major change in the entire epilepsy community, and I remain very proud of that. I am proud of the doors that we have opened in terms of areas of research that we were willing to investigate that others might not have been. I'm proud of the hope and inspiration that we have, again, this wasn't our mission, but that we have offered to families that are going through this. I think we all talk to families with new diagnoses, and I think for them to know as we did not at the time that there is a group out there that's got their backs that is going to do everything they can.
- Barbara Kelly: We have done a lot of the things we wanted to, but we certainly have not achieved our final gold. But I do think we have so many more tools available, and all the genetics and all the tech, and the ability to get the information out that our progress should be at least doubled in the next 10 years. And of course, Susan and I would like to find some major grant that would just take down the walls of epilepsy forever for all.
- Susan Axelrod: Yes, I agree. Really, really anxious to get that big breakthrough, and I think it's got to happen. It's just not going to happen without continued work, continued dollars and the drive of the researchers and the families.
- Kelly Cervantes: It's maintaining that sense of urgency that there are still patients who are dying, and I think we have to hold our foot on the gas pedal, but what the two of you did alongside the rest of the originating CURE Epilepsy Board and the Scientific Advisory Council, and changing that narrative so that it wasn't just living well. The researchers and scientists were all of a sudden contemplating cures, that we weren't settling for treatments. The number of treatments that we have now since 1998, it is innumerable. The advances that we've seen in the technology for brain surgery, for all of these things. And I want to hear from you both, what research or new studies, or findings have you read about recently that is giving you hope?
- Susan Axelrod: I am particularly excited about areas where we may be able to identify who is at risk, for example, with head injuries and how we could intervene beforehand and actually prevent the whole cascade of events that leads to a chronic epilepsy, and that to me is just maybe the lowest hanging fruit. And I feel like if we can tackle one thing at a time and have a great success to celebrate, that will then start to fuel other progress and more, and greater progress. I think as well, of course, the genetics, but there are so many genes associated with epilepsy. And again, do we tackle them one at a time?
- I have to defer to the scientists, and I think one of the things that we always have to know about scientific research is that, you can plan as well as you want. You can be as methodical as you hope, but there is a lot of just plain luck and

being in the right place at the right time, and maybe talking to the right person. We have always believed in bringing people together from different disciplines and the things that people can maybe spark gets lit. There's an idea from something else that could fuel this. So I think it's really hard to be really linear, and I think if you are too much that way, then you also could miss an opportunity. So as much as I would love to say we just need to do A, B, C, D, and we're going to get to our end goal, I think it's not the way science works.

Kelly Cervantes: No, I think you're right. Although, the research coming out of post-traumatic epilepsy and preventing it before it even occurs is so exciting to read up on.

Susan Axelrod: Yes, agreed.

Kelly Cervantes: Barbara, what about you? What areas of research are giving you hope these days?

Barbara Kelly: I also second Susan on the TBI and just early diagnosis, and then intervention and prevention. I mean, if we could do that alone, we would've definitely made a significant advance. But we need to venture out into unknown territory and just take advantage of the new technical advances and that it's incredible what new skills and new tools we have, and we do have wonderful researchers and people working on it. So we need to keep saying, "Thank you, keep working. Do work overtime, please."

Kelly Cervantes: 100%.

Susan Axelrod: I just wanted to add one thing which is, Kelly, I thank you for your appreciation of what came before you, but I want to thank you and your generation for picking up the torch and running with it. I think looking at the next generation and new parents in this field, we don't want anybody to enter our club as we always say, but we're here. I'm so impressed always with, and in part I think it is because the accessibility of information on the internet, but the way new parents are diving in and becoming so educated themselves is just incredible. So while we're happy to have laid a platform groundwork for this, we are so grateful to all of you who are going to keep it going. In the same way that Barbara talked about appreciating the mentors and the research field, I think we will always be, as long as we're around, available to support you and all the other people who are just entering the epilepsy space. But it's a new era, and I think wonderful things can and will happen.

Kelly Cervantes: You two are my mentors. I look up to you, and I am inspired by you daily. And the drive and the fight that you have, 25 years later with this organization, but you've been fighting epilepsy for decades before that, both of you. And so I am so grateful to both of you for taking time out of your day to chat with us and to share this story. And I mean, that's the cherry on top for all of your commitment over decades of work, so I'm just so appreciative to both of you, this entire community is. Thank you.

Susan Axelrod: Thank you, Kelly.

Barbara Kelly: Thank you.

Kelly Cervantes: Thank you Susan and Barb for sharing your stories, memories and hopes for the future with us today. More importantly, thank you for your many years of tireless support and dedication to epilepsy research and for the compassion and advice that you continue to share with families impacted by epilepsy. CURE Epilepsy continues the relentless pursuit of a cure that these two remarkable women started 25 years ago. You can help us achieve our goal of a world without epilepsy by visiting cureepilepsy.org/donate. CURE Epilepsy inspiring hope and delivering impact. Thank you.

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